

CJD 2009 and the CJD Foundation Family Conference

July 10-13, 2009
Washington Court Hotel
Washington, D.C.



Creutzfeldt-Jakob Disease
Foundation, Inc.



PrionNet Canada

CJD Surveillance
National Prion Disease
Pathology Surveillance Center

Tentative Schedule

Friday, July 10

- 9:30 - 10:30** **CJD International Support Alliance (CJDISA) Meeting - Capitol Room**
**This meeting is open only to CJDISA members and invited professionals*
- 11:00 - 1:00** **CJD Foundation Board of Directors' Meeting - Capitol Room**
**This meeting is open only to the members of the CJD Foundation Board of Directors*
- 12:30 - 7:30** **Registration - Atrium Foyer**
- 1:15 - 3:30** **Familial Prion Disease Meeting - Capitol Room**
**This meeting is open only to those families affected by familial prion diseases*
Deana Simpson, RN, Chairman
Macomb, Michigan
Corporate Director of Clinical Transformation, Detroit Medical Center;
Founder and Director, CJD Insight; Member, CJD Foundation Board of Directors
- 3:45 - 5:15** **Bereavement Workshop - Montpelier Room**
Deana Simpson, RN, Chairman
Katrina Hallmark, PsyD
San Antonio, Texas
Neuropsychologist, Southwest Mental Health Center
Marisa Boarman
Akron, Ohio
Associate Director, CJD Foundation; Member, CJD International Support Alliance
- 6:00 - 7:30** **Casual Welcome Reception - Atrium Ballroom**

Saturday, July 11

Atrium Ballroom

Pierluigi Gambetti, MD, Chairman

- 7:00 – 9:30** **Conference Registration – Atrium Foyer**
- 7:00 – 8:00** **Continental Breakfast - Atrium Ballroom**
- 8:00 – 8:10** **Welcome**
Neil Cashman, MD, FRCP(C), FCAHS
Vancouver, Canada
Scientific Director, PrioNet Canada; Canada Research Chair in Neurodegeneration and Protein Misfolding Diseases, University of British Columbia; Director, Vancouver Coastal Health ALS Centre; Founder and Scientific Advisor, Caprion Pharmaceuticals; Founder and Chief Scientific Officer, Amorfix Life Sciences
- 8:10 – 8:40** **Memorial Service**
Florence Kranitz
Akron, Ohio
President, CJD Foundation; Co-Chairman, CJD International Support Alliance
- 8:40 – 8:50** **Introduction**
Pierluigi Gambetti, MD
Cleveland, Ohio
Professor and Director, Division of Neuropathology, Case Western Reserve University School of Medicine and University Hospitals of Cleveland; Director, National Prion Disease Pathology Surveillance Center; Medical Director, CJD Foundation
- 8:50 – 9:20** **CJD Overview**
Robert G. Will, MD, FRCP(E)
Edinburgh, United Kingdom
Professor of Neurology, Personal Chair in Clinical Neurology, University of Edinburgh; Consultant Neurologist, Western General Hospital; Former Director and Founder, National CJD Surveillance Unit

Diagnostic Tests - Blood and Urine

9:20 – 9:40

Neil Cashman, MD, FRCP(C), FCAHS

9:40 – 10:00

Jiri Safar, MD, PhD

Cleveland, Ohio

Co-Director, National Prion Disease Pathology Surveillance Center; Member, European Community Prion Expert Group; Member, World Health Organization Working Group on Prion

10:00 – 10:20

Adriano Aguzzi, MD, PhD, FRCP, FRCPath

Zurich, Switzerland

Professor and Director, Institute of Neuropathology, University of Zurich; Associate Dean, University of Zurich Medical School; President, Swiss Society of Neuropathology; Founder and Director, Swiss National Reference Center for Prion Diseases

10:20 – 10:35

Break

Diagnostic Tests – PMCA

10:35 – 10:55

Claudio Soto, PhD

Houston, Texas

Professor of Neurology and Director, Mitchell Center for Transformational Research in Brain Diseases, University of Texas Medical School; Founder, Vice-President and Chief Scientific Officer, AMPRION Inc.

Diagnostic Tests – MRI

10:55 – 11:15

Alberto Bizzi, MD

Milan, Italy

Neuroradiologist, Fondazione IRCCS Istituto Neurologico “Carlo Besta”

11:15 – 11:35

Michael Geschwind, MD, PhD

San Francisco, California

Assistant Professor of Neurology, Memory and Aging Center, University of California at San Francisco

Treatment

11:35 – 11:55

Review

Richard Knight, MD, FRCP(E)

Edinburgh, United Kingdom

Deputy Director, UK National CJD Surveillance Unit; Professor and Personal Chair, Clinical Neurology, University of Edinburgh; Honorary Consultant, Clinical Neurology, Department of Clinical Neurosciences, Western General Hospital

- 11:55 – 12:15** **John Collinge, MD, FRCP, FRS**
London, United Kingdom
Professor and Head, Department of Neurodegenerative Disease, Institute of Neurology, University College London; Director, UK Medical Research Council's Prion Unit; Director, UK National Prion Clinic, National Hospital for Neurology and Neurosurgery
- 12:15 – 12:35** **Gianluigi Forloni, PhD**
Milan, Italy
Head, Neuroscience Department and Laboratory of Biology of Neurodegenerative Disorders, Mario Negri Institute; President, Italian Association of Brain Aging Research
- 12:35 – 1:35** **Lunch**
- 1:35 – 1:55** **Michael Geschwind, MD, PhD**
- Surveillance**
- 1:55 – 2:15** **Pierluigi Gambetti, MD**
- 2:15 – 2:35** **Gerard H. Jansen, MD, FRCP(C)**
Ottawa, Canada
Neuropathologist, Head of Anatomical Pathology, Principal Investigator, CJD Neuropathology, Ottawa Hospital; Medical Specialist, Prion Diagnostics, Public Health Agency of Canada
- 2:35 – 2:55** **Richard Knight, MD, FRCP(E)**
- 2:55 – 3:15** **Victor Sanchez, MD, PhD**
Guadalajara, Mexico
Director, Centro de Investigaciones Biomédicas de Occidente Laboratorio de Enfermedades Neurodegenerativas
- 3:15 – 5:30** **Moving Round Table Discussion for Researchers and Families**
- 7:00 – 7:30** **Reception – Atrium Foyer**
- 7:30** **Banquet – Atrium Ballroom**

Sunday, July 12

Atrium Ballroom

Florence Kranitz, Chairman

- 7:00 – 8:30** **Continental Breakfast - Atrium Ballroom**
- 8:30 – 8:50** **CJD Foundation Report**
Mark Goldfarb, CPA
Akron, Ohio
Chairman, CJD Foundation Board of Directors
Ruthie George
Akron, Ohio
Treasurer, CJD Foundation Board of Directors; Member, CJD International Support Alliance
- 8:50 – 9:10** **Centers for Disease Control and Prevention Report**
Ryan Maddox, MPH
Atlanta, Georgia
Epidemiologist, Prion Disease Office, Office of the Director, Division of Viral and Rickettsial Diseases, National Center for Zoonotic, Vector-Borne and Enteric Diseases, Centers for Disease Control and Prevention
- 9:10 – 9:40** **The CJD Foundation’s Questionnaire Epidemiology Report**
Steven Korzeniewski, PhD-Candidate, MSc, MA
Lansing, Michigan
Epidemiology Consultant, CJD Foundation; Section Manager, Maternal and Child Health Epidemiology, Michigan Department of Community Health
- 9:40 – 10:00** **American Red Cross Look Back Study Report**
Kerri Dorsey, MPH
Rockville, Maryland
Senior Research Associate and Epidemiologist, Jerome H. Holland Laboratory for the Biomedical Sciences, American Red Cross
- 10:00 – 10:15** **The CJD Foundation’s Research Grant Recipient/Renewal:**
Comparative study of prion strains associated with iatrogenic and sporadic Creutzfeldt-Jakob diseases
Wen-Quan Zou, MD, PhD
Cleveland, Ohio
Assistant Professor, Department of Pathology, Case Western Reserve University; Associate Director of National Prion Disease Pathology Surveillance Center
- 10:15 – 10:30** **The CJD Foundation’s 2009 Research Grant Recipient:**
Pentosan sulphate: A friendly delivery system for therapy in prion diseases
Maurizio Pocchiari, MD
Rome, Italy
Research Director and Head, Clinical, Diagnosis and Therapy of Neurodegenerative Disorders Unit, Department of Cell Biology and Neurosciences, Istituto Superiore di Sanita

10:30 - 10:45 **The CJD Foundation's 2009 Research Grant Recipient:**
Studies of immune responses to PrP during prion infection: role of regulatory T cells
Martine Bruley Rosset, PhD
Paris, France
Research Member and Former Head of Laboratory, Institut National de la Santé et de la Recherche Médicale

10:45 - 11:00 **Break**

Support Organizations

11:00 - 11:15 **CJD Foundation, Mexico**

11:15 - 11:30 **Associazione Italiana Encefalopatie Da Prioni (A.I.En.P.), Italy**
Roberto Borgis
Milan, Italy
President, A.I.En.P.

11:30 - 11:45 **CJD Support Network, United Kingdom**
Richard Knight, MD, FRCP(E)

11:45 - 12:00 **CJD Support Group Network, Australia**
Suzanne Solvyns
NSW, Australia
National Coordinator/Director, CJD Support Group Network;
Co-Chairman, CJD International Support Alliance
Mandy Newton
NSW, Australia
ACCESS Project Manager, CJD Support Group Network

12:00 - 1:00 **Lunch**

1:00 - 2:30 **Advocacy Training**
Washington, DC
Caroline Walker, Legislative Assistant, Senator Jeff Sessions, Alabama

Monday, July 13

Capitol Hill Visits for participating families